

## Regis University ePublications at Regis University

---

### All Regis University Theses

---

Fall 2008

# Palliative Care Patients and their Quality of Life As Perceived By the Patient and their Caregiver

Debra L. Dignan  
*Regis University*

Follow this and additional works at: <https://epublications.regis.edu/theses>



Part of the [Medicine and Health Sciences Commons](#)

---

### Recommended Citation

Dignan, Debra L., "Palliative Care Patients and their Quality of Life As Perceived By the Patient and their Caregiver" (2008). *All Regis University Theses*. 517.  
<https://epublications.regis.edu/theses/517>

This Thesis - Open Access is brought to you for free and open access by ePublications at Regis University. It has been accepted for inclusion in All Regis University Theses by an authorized administrator of ePublications at Regis University. For more information, please contact [epublications@regis.edu](mailto:epublications@regis.edu).

**Regis University**  
Rueckert-Hartman College for Health Professions  
**Final Project/Thesis**

# **Disclaimer**

Use of the materials available in the Regis University Thesis Collection ("Collection") is limited and restricted to those users who agree to comply with the following terms of use. Regis University reserves the right to deny access to the Collection to any person who violates these terms of use or who seeks to or does alter, avoid or supersede the functional conditions, restrictions and limitations of the Collection.

The site may be used only for lawful purposes. The user is solely responsible for knowing and adhering to any and all applicable laws, rules, and regulations relating or pertaining to use of the Collection.

All content in this Collection is owned by and subject to the exclusive control of Regis University and the authors of the materials. It is available only for research purposes and may not be used in violation of copyright laws or for unlawful purposes. The materials may not be downloaded in whole or in part without permission of the copyright holder or as otherwise authorized in the "fair use" standards of the U.S. copyright laws and regulations.

PALLIATIVE CARE PATIENTS AND THEIR QUALITY OF LIFE AS  
PERCEIVED BY THE PATIENT AND THEIR CAREGIVER

By

Debra L. Dignan, MS, PT

A Master's Thesis Presented in Partial Fulfillment  
Of the Requirements for the Degree  
Master of Science, Health Service Administration

Regis University

December, 2008

FINAL APPROVAL OF MASTER'S PROJECT

**HSA696 MASTER'S PROJECT**

I have **READ AND ACCEPTED**

the Master's Project by:

Debra L. Dignan

Palliative Care Patients and Their Quality of Life as Perceived by  
The Patient and Their Caregiver.

Submitted in partial fulfillment of  
requirements for the  
Master of Science in Health Services Administration  
degree at  
Regis University

Primary Research Advisor: Janet Houser PhD

Date: December, 2008

### Abstract:

This quantitative pilot study examined the quality of life of palliative care patients as perceived by the patient and their caregiver. Patients with palliative care consults at The University of Colorado and The Medical Center of Aurora were asked to participate in this study. The McGill Quality of Life Questionnaire survey tool was selected to measure the patient's quality of life due to its validity and reliability in measuring quality of life in the palliative care patient population. The McGill Quality of Life Questionnaire consists of five distinct subscales: physical well-being, physical symptoms, psychological symptoms, existential well-being, and support. Sixteen patients and eight caregivers completed the survey.

Results: The results of paired samples tests demonstrated p-values that were not statistically significant for the five subscales measured. They indicated weak evidence against the null hypothesis. Based on the p-value results the null hypothesis can not be rejected. Based on the Cronbach's alpha the internal consistency (reliability) for this study for the patient scores was 0.625 and for the families it was 0.606 which does not meet the standard of 0.70 or greater. If item number eight was removed from both the patient and the family questionnaires the Cronbach's alpha increased to 0.691 and 0.706 respectively. The study indicated a weak correlation between the patient and family subscales.

Discussion: Based on the small sample size the weak correlation could be anticipated. Further research is warranted to see if, given a larger sample size, the reliability could be improved and a finding illuminated. Detection of differences may have been missed due to the small sample size and inadequate illumination.

## Acknowledgements

I would like to thank the following individuals for their love and support. Without them this journey would not have been possible. I would like to thank my husband, Jerry, for his constant love, support, and encouragement to “Grow my brain”. Thank you to my son, Justin, for his “tech support” and my daughter, Brittany, for being my biggest cheerleader. Thank you to my wonderful parents for always believing I could do anything. This Master’s Project is dedicated to my brother-in-law, Dan, for inspiring me every day. Your spirit lives on....

## Table of Contents:

Chapter 1: Introduction.....	1
Purpose: .....	2
Research Question: .....	3
Null Hypothesis:.....	3
Chapter 2: Literature Review .....	6
Palliative Care: .....	8
Definition. ....	8
Classification. ....	9
Key principles.....	9
Growth. ....	10
Quality of Life:.....	10
Definition. ....	10
Assessment/measurement. ....	12
Proxy rating. ....	13
Dr. Jean Kutner.....	13
End of life care. ....	14
Seminal Works: .....	14
SUPPORT Study. ....	15
Disability paradox.....	15
Dr. Robin Cohen.....	16
Systematic literature review. ....	16
System distress. ....	16
Hospital-based palliative care. ....	16
Relationship between symptom relief. ....	17
Caregiver:.....	17
Cost/Reimbursement: .....	18
Medicare hospice benefit. ....	18
Patient self-determination. ....	19
Regulatory Concerns. ....	19
Conclusion: .....	19
Chapter 3: Methods and Materials .....	21
Research Design: .....	21
Sampling Strategy: .....	21
Measurement Strategy: .....	22
Patient survey tool. ....	22
Data Collection:.....	23
Data Analysis Method: .....	23
Conclusion: .....	23
Chapter 4: Results .....	24
Characteristics of Patient Respondents.....	24
Description of Instrument Characteristics. ....	25
Troublesome symptoms. ....	26

Figure 1: Frequency of Troublesome Symptoms Reported First .....	26
Figure 2: Frequency of Troublesome Symptoms Reported Second.....	27
Scoring. ....	27
Analysis of Relationships and Differences. ....	28
Descriptive Statistics for Subscale Scores. ....	28
Correlation Analysis and Results. ....	29
Paired Sample t-test.....	30
Chapter 5: Discussion.....	32
Recommendations for further study. ....	32
Reference List: .....	34
Appendix A:.....	38
Appendix B: .....	39



## Chapter 1: Introduction

Historically the focus of medicine in the United States has been on curing illness and disease. There has been great emphasis placed on technology and clinical interventions. There are numerous healthcare challenges that are pushing us towards a paradigm shift in the way that health care is being delivered. These challenges include societal, demographic, financial, human suffering, regulatory, and reimbursement issues (Fine, 2004).

Despite improvements in technology and the treatment of disease many patients report a high degree of pain and symptom distress in hospitals. According to Nelson 55-75% of patients experience pain, discomfort, anxiety, sleep disturbances, and unsatisfied hunger while hospitalized (Nelson, 2001). “Despite the finding that when polled more than 90% of Americans say they would prefer to die at home, more than 75% of adult deaths occur in institutional settings (hospitals or nursing homes) – more than 50% in hospitals and 25% in nursing homes” (Meier, 2006 p 22). In the early 1900’s death was seen as a natural part of life. Death frequently occurred in the home with family and friends close-by. Our current health care model has depersonalized death and moved it away from the home to more of an institutional setting.

The problem with the current medical model in the United States is that it does not do a good job in addressing the non-physical aspects of illness, which include the emotional, psychological, and spiritual needs of patients and caregivers. The current model also does not adequately address the quality of life and practical burdens that are faced by patients and caregivers dealing with chronic or terminal illnesses. Future research needs to address the role that palliative care programs can play in addressing these issues (Fine, 2004).

Palliative care programs offer an alternative approach to manage the challenges of healthcare today. Palliative care has been defined as “medical care focused on the relief of suffering and

support for the best quality of life for patients facing serious, life-threatening illness and their families. It aims to identify and address the physical, psychosocial, and practical burdens of illness” (Meier, 2006 p 21). Palliative care began as a part of the hospice movement that developed in both the United Kingdom and the United States approximately thirty years ago. The goal of palliative care is to relieve suffering and symptoms (including pain, psychological, spiritual, physical) and to improve the quality of life for the patient and family. Palliative care is different from hospice care in that the patient can continue to pursue aggressive treatment. Hospice is a philosophy of care. It began in its earliest days as a form of ‘hospitality’ to travelers who needed rest or shelter. It focuses on the patient and not the disease itself. Hospice is appropriate when treatment is no longer an option for the cancer or other life-threatening illness and the life expectancy is six months or less. The goal of hospice care is to manage the symptoms of the disease so that the patient can remain alert and pain free during the last few days of their life. The goal is to allow the patient to die with dignity and as free as possible from symptom distress. The growth in numbers of both seriously and chronically ill patients has fostered the need for palliative care programs (Meier, 2006).

*Purpose:*

The purpose of this study is to determine if there is a difference in the perceptions of the palliative care patient’s quality of life as measured by the patient and their caregiver. Our current healthcare model does not do a good job in addressing the non-physical aspects of illness, which include the emotional, psychological, and spiritual needs of patients and caregivers. The purpose of this study is to determine what are the important domains related to quality of life as perceived by the patient and their caregiver.

*Research Question:*

The research question was: For patients enrolled in a palliative care program, is there a difference in the patient's perception of their quality of life and their caregiver's perception of the patient's quality of life as measured by The McGill Quality of Life Questionnaire?

*Null Hypothesis:*

There will be no difference in the patient's perception of their quality of life and their caregiver's perception of their quality of life as measured by The McGill Quality of Life Questionnaire.

Palliative care programs are of great interest to hospital administrators because they offer solutions to the healthcare challenges facing hospitals today. These challenges include demographic, financial, human suffering, regulatory, and reimbursement. The challenge of the changing healthcare demographic is troubling. "With the aging population the number of patients with chronic illnesses has been growing steadily. In 2000, 122 million people had chronic illnesses; the numbers are projected to be 132 million in 2005, 140 million in 2010 and > 170 million in 2030" (Fine, 2004 p 260).

With advances in health care and technology many patients who would have died in the past are now living years with diseases that would have caused their death. This presents challenges for health care administrators because health care resources and finances are finite. As the population in the United States continues to age, the number of individuals facing chronic disease will increase. Caregivers are now caring for many of these patients at home with no formal training in the sometimes-complicated medical therapies. This has placed additional burdens on the caregiver. A study conducted in 1994 titled the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) study demonstrated that the financial burdens on caregivers is also a factor. The study concluded that one-fifth of all family

members caring for seriously ill family members had to quit their jobs, almost one-third reported the loss of most of their savings, and 29% reports loss of family income (Deeken, et al, 2003).

Financial challenges are important to health care administrators. There is increasing scrutiny by third-party payers for value and accountability with regards to healthcare costs. According to Fine “Thirty percent of Medicare costs cover care for the sickest 5% of patients and 70% of overall health care costs cover care for the sickest 10% of the population. Of the \$242 billion in Medicare expenditures in 2001, 26%, or \$63 billion, was spend during the last 12 months of life and 14%, or \$34 billion, was spent in the last 2 months of life” (Fine, 2004 p 260). “Health care costs have risen nearly 10% per year in each of the last two years because of both the increasing numbers of patients turning to them for care and the number and expense of effective life-prolonging therapies” (Meier, 2006 p 23).

Palliative care programs have been shown to reduce direct costs for hospitals as well as third party payers. “Mount Sinai Hospital saved \$757,555 in 1 year by implementing its palliative care service for patients who had been in the hospital for 2 weeks or more. Kaiser Permanente conducted a retrospective review of costs for patients who died on usual care vs. those who died on palliative care and found a \$6,586 reduction per patient on palliative care”(Fine, pg 261, 2004). According to Campbell “hospital palliative care programs suggest positive patient and system outcomes including improved symptom management, patient and family satisfaction, increased deaths at home, and reduced hospital length of stay” (Campbell, 2006 p 356).

Another important area that hospital administrators would be interested in is their patients’ quality of life or the absence of suffering. Although many technological advances have been made there remains a lack of understanding on the part of health care providers on the scope of suffering. “In addition to physical distress, life-altering changes such as loss of career, loss of

hope, loss of independence, isolation, depression, and guilt may contribute to suffering” (Abraham, et al, 2006 p 659).

A study by Abraham et al concluded that “relief of pain is just one of many dimensions which affect quality of life near life’s end and additional factors that have been found to enhance quality of life include relieving burden on family members, strengthening relationships among loved ones, achieving a sense of control and satisfaction with hospice care” (Abraham et al, 2006 p 662). Hospital administrators would find this information of value in understanding more clearly all of the factors that influence patient and caregivers perception of their quality of life. Administrators are challenged with balancing both the financial health of their organization with providing the highest quality, evidence-based care available.

According to Dr. Fine “palliative care relieves pain and distressing symptoms, supports ongoing reevaluation of goals of care and difficult decision making, improves quality of life, improves satisfaction for patients and their families, eases burdens on providers and caregivers, and improves transition management” (Fine, 2004 p 261).

Regulatory concerns are a continuing issue and challenge for healthcare administrators. “Regulations of the Joint Commission on Accreditation of Healthcare Organizations encourage palliative care, and US News and World Report will begin ranking hospitals in the category of palliative care services” (Fine, 2004 p 262). The Joint Commission on Accreditation of Healthcare Organizations will continue to look at the areas of pain management, communication, patient/family education, and continuity of care. These are all areas that a palliative care program would assist in addressing. As healthcare consumers become more educated about their options, hospital rankings will become increasingly important in order for hospitals to remain competitive. Patients will make many of their healthcare choices based on rankings and reported

clinical outcomes. Reimbursement issues are another important consideration. In order for Medicare and other commercial insurance carriers to cover hospice care the physician must make a prognosis that the patient has six months or less to live. For most of its thirty-year history in the United States palliative care has been delivered through hospice programs. Palliative care programs offer one option for healthcare administrators in their challenge to provide high-quality, cost effective care while continuing to meet the financial, regulatory and competitive demands present in healthcare today. These programs also support the physical, emotional, and spiritual needs of patients and their caregivers dealing with chronic disease. “In principle, people want a peaceful, dignified, comfortable death...in reality, they do not want it quite yet” (Ainslie, 1997 p 242).

The difference in the perception of quality of life according to the patient and caregiver would be important for healthcare administrators to more fully understand. If differences do exist then interventions can be developed to support the needs of both the patient and the caregiver. Since the focus of palliative care programs is to support the patient who suffers from a chronic or terminal illness, the caregiver’s perception is often overlooked. If there is an observed difference this study would allow healthcare administrators the information to design interventions that assist both the patient and the caregiver. “Helping the family cope with these severe stressors is not only a humane component of end-of-life care, but is also an important step in facilitating a good death for the patient” (Block, 2006 p 755).

## Chapter 2: Literature Review

Health care in the United States today is focused on technology and clinical interventions for the treatment and cure of chronic illness and disease. Our current healthcare system is facing

many challenges including societal, demographic, financial, human suffering, regulatory and reimbursement issues (Fine, 2004). According to Morrison “the United States faces the largest public health challenge in its history namely, the growth of the population of older adults. Improvements in public health, the discovery of antibiotics, and advances in modern medicine has resulted in unprecedented gains in human longevity” (Morrison, 2005 p S-79).

As the population in the United States continues to age, more and more individuals are facing chronic illnesses such as “heart or lung disease, Alzheimer’s disease and related dementias, stroke, neuromuscular degenerative diseases, AIDS, and many malignancies. The time before death is characterized by months to years of physical and emotional symptom distress, progressive functional dependences and frailty, and high family support needs” (Morrison, pg S-80, 2005). “By the year 2030 one in five adults will be over the age of 65 years as compared to one in twenty in 1900” (Morrison, 2005 p S-79).

Despite improvements in technology and the treatment of disease many patients report a high degree of pain and symptom distress in hospitals. According to Nelson (2001) 55-75% of patients experience pain, discomfort, anxiety, sleep disturbances, and unsatisfied hunger while hospitalized. “Despite the finding that when polled more than 90% of Americans say they would prefer to die at home, more than 75% of adult deaths occur in institutional settings (hospitals or nursing homes) – more than 50% in hospitals and 25% in nursing homes” (Meier, 2006 p 22). In the early 1900’s death was seen as a natural part of life. “Consumers and providers alike continue to indict the American way of death as fragmented, expensive and insensitive to patient and family preferences despite substantial nationwide improvements in care for dying patients” (Tilden, 2002 p 71). Healthcare consumers are requiring that our current healthcare system address these important domains.

Another concern regarding our current health care model relates to the education and focus of physicians. “Physicians typically conceptualize medical care as having two mutually exclusive goals – either the cure of disease and life prolongation or comfort/ end-of-life care as exemplified by hospice” (Morrison, 2005 p S-81). These two goals should ideally work in concert to provide life-prolongation therapies while at the same time focusing on symptom relief as well as supporting the psychosocial and spiritual needs of the patient and caregiver.

The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT), which included more than 9,000 adults hospitalized with serious chronic illness documented unacceptably high levels of untreated physical symptoms, minimal advanced care planning, treatment decisions in conflict with patients previously stated wishes, and sites of death discordant with patients expressed preferences (Morrison, 2005 p S-80).

The problem with our current medical model is that it does not do a good job in addressing the non-physical aspects of illness, which include the emotional, psychological, and spiritual needs of patients and caregivers. The current model also does not adequately address the quality of life and practical burdens that are faced by patients and caregivers dealing with chronic or terminal illnesses. Future research needs to address the role that palliative care programs can play in addressing these issues. There is a gap between the care provided by Medicare and other payers and hospice care for patients dealing with chronic and life-threatening illnesses. Palliative care programs may fill this gap in healthcare.

#### *Palliative Care:*

*Definition.* Palliative care has been defined as “medical care focusing on the relief of suffering and support for the best quality of life for patients facing serious, life-threatening illness and their families. It aims to identify and address the physical, psychosocial and practical



burdens of illness” (Meier, 2006 p 21). “The goal of palliative care is to optimize the quality of life of patients with advanced incurable disease through control of physical symptoms and attention to the patients psychological, social and spiritual needs” (Jochman, 2006 p 1188). The World Health Organization defines palliative care as programs that “improve the quality of life of patients and families who face life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems – physical, psychosocial and spiritual” (<http://www.who.int>).

Palliative care began as part of the hospice movement that developed in both the United States approximately thirty years ago. Palliative care is different from hospice care in that the patient can continue to pursue aggressive treatment. The focus of palliative care is on symptom management and not on curing the illness or disease. Its role is to improve the quality of life of patients and caregivers dealing with chronic or terminal disease (Meier, 2006).

#### *Classification.*

According to Kaasa (2003) palliative care can be classified in the following ways:

Primary palliation	> 6 months expected survival
Early palliation	2-3 months expected survival
Late palliation	1 month expected survival
Imminently dying	1-2 weeks expected survival

*Key principles.* Maher (pg 319) describes key principles of palliative care when advanced disease indicates that cure is not a feasible option. The principles include the following: provide relief from pain and other symptoms; integrates psychological and spiritual aspects of patient care; offers a supportive system to help patients live well until death; is concerned to bolster family coping during illness and bereavement; may be applicable at any stage of the illness

journey. These principles help to define the measurable outcomes that are important to determine if a palliative care program is meeting the needs of patients and caregivers. Since the goal of palliative care is to optimize the quality of life of patients with incurable disease “the outcomes of care should be measured in terms of the extent to which this goal is achieved (Jochman, 2006). In order to measure the extent to which these goals are met, several organizations have advocated for a single assessment tool that would measure the outcomes of palliative care programs. These include the Gold Standard Framework published by Macmillan Cancer relief ([www.macmillan.org](http://www.macmillan.org)) and policies such as the NHS Cancer Plan (Maher).

*Growth.* According to Byock there are more than 1,000 hospital-based palliative care programs in the United States with many more programs coming into existence. Evidence-based research is necessary to ensure that these programs are meeting the needs and providing quality outcomes for patients and caregivers. Byock also notes that “US News and World Report now include hospital palliative care as criterion in selecting institutions for its annual list of 50 best hospitals (Byock, 2006 p S-302). As healthcare continues to become more competitive and healthcare consumers become more educated such designations will become increasingly more important to the financial well being of hospitals.

#### *Quality of Life:*

*Definition.* In order to more fully understand the goals of palliative care programs it is important to define what is meant by quality of life. There are many definitions presented in the literature reviewed. One definition as defined by the World Health Organization includes looking at six different domains. These domains include: physical health, psychological state, levels of independence, social relationships, environmental features, and spiritual concern (Jochman, 2006 p 1191).

Dr. Robin Fainsinger defines quality of life as maximizing patient and family comfort across four broad domains: the physical, psychological, spiritual, and existential. Mariela Bertolino defines quality of life as physical symptoms, psychological distress, social and financial issues. Each of these is in turn related to spiritual or existential problems and is key to defining quality of life. Bruley describes four main concepts of quality of life: social utility, happiness/affect, life satisfaction, and normal life – functional status. Each of these definitions is similar and includes the major domains that are the goals of palliative care programs. Without the context of the definition of quality of life it is difficult to assess and to understand what factors may impact quality of life.

Other definitions include the following theories as related to quality of life: Maslow's hierarchy of needs which defines quality of life as the ability to meet all of the levels of the hierarchy including physical, safety, love and belonging, self-esteem, and self actualization ([www.chiron.valdosta.edu](http://www.chiron.valdosta.edu)). The Gap-Theory by Calman defines the quality of life as “the inverse relationship of the difference between an individual's expectations and their perceptions of a given situation. The smaller the gap the better the quality of life” (Kaasa, 2003 p 12).

The literature also points to a more specific measurement of quality of life referred to as health-related quality of life. According to Kaasa “this approach defines quality of life as a global, overall perspective, which includes in its scope one's philosophical perspectives on life. It challenges the health-related orientation and draws attention toward asking the patients not only to rate their symptoms or worries, but to also give relative value to them” (Kaasa, 2001 p 414). These definitions are important to give researchers a common place from which to measure quality life.

*Assessment/measurement.* There is numerous assessment tools developed to measure patients quality of life. There is no gold standard assessment tool of quality of life. These measurement tools are important in order to assess the effectiveness of various treatments within a healthcare program. The results can provide evidence-based data to prove certain treatments are or are not effective in improving a patient's quality of life. By measuring quality of life we can learn more about which domains affect quality of life and therefore tailor treatment programs to more effectively meet these needs. Outcome measurements are becoming increasingly more important to payers and patients alike as a measurement of cost-effective quality care.

There are two main models used in the research of quality of life in cancer patients. These include The City of Hope model (Ferrel, 1991) and the Quality of Life model (Ferrans and Powers, 1995). These models were developed to assist in developing theory around the domains of quality of life. They have each been modified for use with patients other than cancer patients. They both view quality of life from a multi-dimensional and subjective perspective.

Kaasa reports that “outcome measures in palliative care require constructs that reflect specific goals of palliative care, such as improving quality of life before death, symptom control, family support and satisfaction as well as patient/family perceptions of ‘purpose’ and ‘meaning’ of life” (2003 p 11). His study suggests that questionnaires measuring quality of life be multidimensional, patient rated and thoroughly evaluated for their content validity and reliability.

The literature cites numerous barriers to the measurement of quality of life in the palliative care population. According to Tilden “challenges include difficulties in defining end-of-life time periods to delineate the denominator for statistical analyses; controlling for extraneous influences or other interactions on the variability of constructs; minimizing subject burden while maximizing robustness of a scale; and using proxies as respondents for a patient population that

is largely incapacitated at the final stage” (Tilden, 2002 p 71). Cohen’s research indicates that quality of life is difficult to assess “due to lack of outcome measures for this phase of life and due to patients conditions and ability to participate in studies/interviews due to their illness” (Cohen, 2001 p 364). She goes on to report that controlled trials have been very difficult to complete in this patient population due to ethical issues and concerns that such studies may raise. According to Tilden “measurement bridges the conceptual and operational levels of scientific research, clinical care and quality improvement” (2002 p 79).

The McGill Quality of Life Questionnaire is one of the more commonly used assessment tools in the palliative care population. Dr. Robin Cohen and Dr. Balfour Mount of the Division of Palliative Care, Department of Oncology, McGill University developed this tool. This tool was designed to provide a valid measure of quality of life with the terminally ill from the time of diagnosis to death. It is composed of seventeen items derived from patient interviews, literature review and existing instruments. The major areas addressed by this assessment tool include: physical well-being, physical symptoms, psychological symptoms, existential well-being, and supportive relationships.

*Proxy rating.* There is much debate in the literature regarding the use of proxy ratings to measure quality of life for patients in palliative care programs. There are studies that both support and refute the use of proxy ratings. Most agree that when possible, patients should be the primary source for gathering quality of life information. According to Bridge in her study she concluded that information supplied by a proxy may differ from that of the patient and is the perspective of the proxy and not necessarily that of the patient (Bridge, 2002).

*Dr. Jean Kutner.* In the research study conducted by Dr. Jean Kutner, et al, entitled “Symptom Distress and Quality-of-Life Assessment at the End of Life: The Role of Proxy

Responses” the purpose was to “advance understanding of the relationship among proxy and patient reports of symptom distress and quality of life”. The study used both the Memorial Assessment Scale (MSAS) and the McGill Quality of Life Questionnaire (MQOL) at enrollment to hospice/palliative care programs. The surveys were repeated at one week, two weeks, and then monthly until death or discharge from the program. The study results demonstrated that “patients and proxies provided similar average reports of symptom distress, both physical and psychological, but MSAS correlations were generally poor. MQOL correlations were higher for nurse-patient than for patient-caregiver dyads” (Kutner, 2006 p 300). This study demonstrated that proxy responses could be a fair substitute for patient responses related to symptom distress and quality of life. The study also demonstrated that data should be gathered from all available resources related to patient’s symptom distress and quality of life.

When using proxy respondent it is important to note that they can be a fair substitute for patient responses but that they can differ from the patient responses. This study will add to the body of knowledge related to both patient and proxy respondents as it relates to quality of life.

*End of life care.* End of life care has become more important to both payers and patients as healthcare expenses rise and patients are interested in the most cost-effective, evidence-based care possible. The Institute of Medicine has developed outcomes for the measurement of end-of-life care. These include the patient’s perception of care and psychological well being and functioning. These measurement outcomes are useful for comparing the effectiveness of treatment outcomes and the overall effectiveness of palliative care programs.

*Seminal Works:*

There are many studies measuring the quality of life of patients in palliative care programs. The literature cites studies that both support and refute the conclusion that palliative care programs improve the quality of life for patients involved in these programs.

*SUPPORT Study.* One of the most significant studies on this topic was the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT) study. This landmark study was conducted over a four-year period of time and involved over 9,000 patients. This study was completed in 1994 and had two phases. Phase I: The purpose was to “improve end-of-life decision making and reduce the frequency of mechanical support and painful and prolonged treatment patterns prior to death” (Greipp, 1996 p 42).

Phase II: This phase was comprised on a two-year controlled clinical trail with 4,804 clients and their physicians. It was composed of a control group component and an intervention group component” (SUPPORT study, 1995 p 1592). The results of the SUPPORT study did not demonstrate improvements in the intervention group over the control group for physician communication or other study outcomes. There was also no cost reduction in hospital resources.

*Disability paradox.* Kutner and colleagues completed a study entitled “Confirmation of the ‘disability paradox’ among hospice patients: Preservation of quality of life despite physical ailments and psychosocial concerns”. The results of this study demonstrated that patients involved in palliative care programs had a strong sense of hope and spiritual connection despite facing a terminal illness. It also demonstrated that their quality of life persisted and they maintained a positive outlook. (Kutner, 2003). This research study is important to determine if patients enrolled in a palliative care program do maintain a strong sense of hope and a positive attitude despite their terminal illness. Dr. Kutner’s study supports that this is true.

*Dr. Robin Cohen.* In the study done by Dr. Robin Cohen, et al, entitled “Changes in quality of life following admission to palliative care units” she used the McGill Quality of Life Questionnaire to determine the patient’s quality of life on admission to palliative units and then 7-8 days later. Patients were asked to describe the nature of changes in their quality of life since admission to a palliative care program. The study demonstrated that “significant improvements were found in the MQOL total score and subscale scores reflecting physical, psychological and existential well-being. In interviews patients indicated that they had experienced changes in physical, emotional and interpersonal status, in spiritual outlook, and in their preparation for death. This is the first study to demonstrate that hospice/palliative care can improve existential well-being in addition to psychological and physical symptoms” (Cohen, 2001 p 363).

*Systematic literature review.* Another important study was titled “The impact of different models of specialist palliative care on patient’s quality of life: A systematic literature review (Salisbury, 1999). Study findings report some evidence that inpatient palliative care programs provide better pain control than home care or hospice care. The study reported little impact on quality of life over conventional care.

*System distress.* In the study “Time course and characteristic of symptom distress and quality of life at the end of life” (Kutner, 2007). The study findings reported the persistence of significant symptom distress, especially due to pain, in patients involved in palliative care programs. Her study calls for more research to provide clinical guidance to improve care provided in the last days of life.

*Hospital-based palliative care.* In the study “Palliative care consultation in the intensive care unit” (Campbell, 2006 p S-355) the findings support that hospital-based palliative care programs have demonstrated “positive patient-assessed and system outcomes, including symptom



management, family support, reductions in hospital length of stay, increases in discharge home with hospice referrals, and reduced cost of care”.

*Relationship between symptom relief.* In the study by Tierney “Relationships between symptom relief, quality of life, and satisfaction with hospice care” the results demonstrated satisfaction with hospice care was more associated with quality of life than symptoms. The study found that symptoms became more important closer to the end of life. (Tierney, 1998).

#### *Caregiver:*

The role of the caregiver for patients with chronic disease or terminal illness bears further study. The literature has limited research related to this topic. Due to the shift in the United States from an inpatient to an outpatient setting, more and more patients are relying on family members or caregivers to provide care that was previously accomplished by trained health care workers. Many times this care requires technical skills or interventions that the caregivers are not adequately trained to do.

The SUPPORT study in 1994 reported that “one-fifth of all family members of seriously ill patients had to quit work or make another major life change in order to care for their family members. Almost one-third reported the loss of all of their family savings, and 29% reported the loss of the major source of family income” (Deeken, 2003 p 923). Due to the shift in healthcare in the United States from hospital care to outpatient care it is more important to support and understand the needs of caregivers. Since most of the care at home is provided by family members and not paid personnel, “it is estimated that all of the care provided to critically ill and disabled adults in America by informal caregivers is valued at \$196 billion a year” (Deeken, 2003 p 923).

*Cost/Reimbursement:*

*Medicare hospice benefit.* Financial challenges are important to health care administrators. There is increasing scrutiny by third-party payers for value and accountability with regards to healthcare costs. According to Fine “Thirty percent of Medicare costs cover care for the sickest 5% of patients and 70% of overall health care costs cover care for the sickest 10% of the population. Of the \$242 billion in Medicare expenditures in 2001, 26%, or \$63 billion, was spend during the last 12 months of life and 14%, or \$34 billion, was spent in the last 2 months of life” (Fine, pg 260, 2004). “Health care costs have risen nearly 10% per year in each of the last two years because of both the increasing numbers of patients turning to them for care and the number and expense of effective life-prolonging therapies” (Meier, 2006 p 23).

Palliative care programs have been shown to reduce direct costs for hospitals as well as third party payers. “Mount Sinai Hospital saved \$757,555 in 1 year by implementing its palliative care service for patients who had been in the hospital for 2 weeks or more. Kaiser Permanente conducted a retrospective review of costs for patients who died on usual care vs. those who died on palliative care and found a \$6,586 reduction per patient on palliative care”(Fine, 2004 p 261). According to Campbell “hospital palliative care programs suggest positive patient and system outcomes including improved symptom management, patient and family satisfaction, increased deaths at home, and reduced hospital length of stay” (Campbell, 2006 p 356). Morrison reports that the “reimbursement system fails to address many of the needs of patients with serious and chronic illness. Medicare is targeted to acute episodic illness and is ill equipped to respond to the long-term needs of the chronically ill. Since 1982 the Medicare hospice benefit provides care for patients when certified by their physician that they are within six months of death provided they not pursue life-prolonging treatment. Most patients don’t fit the disease model as their disease course is not easily defined and the prognosis is difficult to predict” (Morrison, 2005 p S-80). For

most of its thirty-year history in the United States palliative care has been delivered through hospice programs. Most insurance carriers do not cover non-hospice palliative care.

*Patient self-determination.* The Patient Self-determination Act of 1990 requires that “all institutions receiving Medicare and/or Medicaid funding provide every adult client with written information about ‘patient rights’ including the right to be involved in treatment decisions” (Greipp, 1996 p 38). The literature review supports that this was an important step in supporting the growth in palliative care programs.

*Regulatory Concerns.* Regulatory concerns are a continuing issue and challenge for healthcare administrators. “Regulations of the Joint Commission on Accreditation of Healthcare Organizations encourage palliative care, and US News and World Report will begin ranking hospitals in the category of palliative care services” (Fine, 2004 p 262). The Joint Commission on Accreditation of Healthcare Organizations will continue to look at the areas of pain management, communication, patient/family education, and continuity of care. These are all areas that a palliative care program would assist in addressing. As healthcare consumers become more educated about their options, hospital rankings will become increasingly important in order for hospitals to remain competitive.

#### *Conclusion:*

The goal of palliative care is to provide the best quality of life for patients and their caregivers. Much of the research has been focused on defining the domains that determine an individual’s quality of life. The research has been divided on the whether or not palliative care programs do indeed improve the quality life for patients. The literature review concluded that more studies support the view that these programs do improve the quality of life of patients. More research is needed to determine which domains are most important and what intervention

impact each of these domains. The other important area of research that deserves further study is the role that palliative care programs play in the quality of life for caregivers, especially in the area of caregiver burden. Healthcare administrators would be interested in the outcomes of such studies due to the growth in palliative care programs and the fact that the literature does support that they can help achieve quality outcomes and reduce healthcare costs. There remains a gap between the traditional medical coverage by Medicare and other payers and hospice care for patients dealing with chronic and life-threatening illness. Palliative care programs may help to fill this gap by providing alternatives that better meet the physical, psychological, social, and spiritual needs of patient and their caregivers.

This study is important in adding to the current body of knowledge related to the use of proxy respondents in the area of quality of life of patients. It is also important to gain more information related to the effect of palliative care programs on caregiver burden. Finally, the important research question to understand if there is a difference between patients and their caregivers when measuring the patient's quality of life.

### Chapter 3: Methods and Materials

#### *Research Design:*

This quantitative survey design pilot study was designed to measure the quality of life of patients enrolled in palliative care programs as perceived by the patient and their caregiver. The purpose of this study is to determine if there is a difference between the perception of the patient's quality of life and their caregiver's perception of the patient's quality of life. The rationale for using this research method is that it would allow the researcher to gather information regarding the patient and caregiver's experiences, attitudes, and perceptions about quality of life.

#### *Sampling Strategy:*

The sample for this study was patients and their caregivers participating in a palliative care program at The University of Colorado. The sample also included HealthONE patients who have a palliative care consult and their caregivers. Participants must be 18 years or older and English speaking to participate in this study. Primary caregiver is defined as the person providing the most care for the patient and not paid to provide the care.

The sample size was calculated using the number of respondents needed for each of the questions on the survey tool. The goal was to have fifteen responses to each question. Due to the study population attrition due to death and difficulty completing the survey was anticipated and factored into the projected sample size.

The survey tool and introductory letter was reviewed with the study participant by the researcher. The following demographic information regarding the patient was also obtained; age, sex, ethnicity, living situation, number of children, religious belief/spirituality, importance of religion/spirituality, education level, type of insurance and type of illness (Appendix A). Internal

review board approval was obtained from COMIRB, Regis, and the HealthONE hospital systems. Completion of the survey implied consent. Completed surveys were returned to the researcher in preaddressed stamped envelopes or at the end of the interview session.

*Measurement Strategy:*

*Patient survey tool.* The McGill Quality of Life Questionnaire (MQOL) was used to measure the quality of life of patients receiving palliative care services. Both the patient and their caregiver completed the survey tool. The caregiver completed the survey tool as they rated the patient according to the question being asked. The McGill Quality of Life Questionnaire is one of the more commonly used assessment tools in the palliative care population. This tool was developed by Dr. Robin Cohen and is composed of seventeen items derived from patient interviews, literature review and existing instruments. The major areas addressed by this assessment tool include: physical well-being, physical symptoms, psychological symptoms, and existential well-being (Appendix B).

One of the reasons this tool is so widely used is its proven reliability and validity in the palliative care population. “The reported cronbach alpha coefficients indicate that the internal consistency (reliability) of the MQOL subscales and the complete scale are good (total MQOL alpha = 0.88; physical symptoms alpha 0.62; psychological symptom alpha 0.81; existential well-being alpha 0.79; support alpha 0.74). Validity is supported by the observation that the MQOL total score predicts the single item scale (SIS) score” (Kutner, 2006 p 303). This tool was selected due to its psychometric properties and because it is one of the few tools noted to be both reliable and valid for this patient population. Permission was obtained from Dr. Robin Cohen to use the McGill Quality of Life Questionnaire survey tool. The appropriate user and information registration forms were completed.

*Data Collection:*

The data was collected between June 1<sup>st</sup> and October 1st, 2008. No data were collected until the appropriate Internal Review Board approval had been completed. The primary researcher recorded the data using an excel spreadsheet. The data were stored on the personal computer of the researcher and all data was backed-up.

*Data Analysis Method:*

The SPSS statistical software program version was used to analyze these data. The MQOL questionnaire is a Likert scale, which means it is an ordinal scale. Appropriate descriptive analysis was used to summarize the data. Cronbach's alpha was calculated to determine sample-specific reliability. Pearson's chi square was used to determine differences in responses between patients and their caregivers on responses on the instrument.

*Conclusion:*

The results of this study will help to contribute to the body of knowledge related to the role of palliative care and quality of life. More specifically the study aims to determine if there is a difference between the patient's perception of their quality of life and the caregiver's perception of the patient's quality of life. The studies aim is to identify which indicators are most important in determining quality of life for patients and caregivers. Healthcare administrators can ensure programs that focus time, energy, and resources devoted to these important indicators. The study will be important to healthcare administrators.

## Chapter 4: Results

This pilot quantitative survey design was used to measure the quality of life of patients enrolled in palliative care programs as perceived by the patient and their caregiver. Due to the limited sample size this study was a pilot study. The sample included sixteen patient respondents and eight caregiver respondents. The age range of patient respondents was 41 years to 86 years of age with the mean age of 64.4 years. Seven male patients completed the survey (43.8%) while nine female patients completed the survey (56.3%). The results of the demographic questions are included in the following table:

### *Characteristics of Patient Respondents*

	Frequency	Valid Percent
<b>Ethnicity</b>		
White	10	62.5
Black	1	6.3
Hispanic	4	25.0
Other	1	6.3
Total	16	100.0
<b>Living Situation</b>		
Single	5	31.3
Married	6	37.5
Divorced	3	18.8
Widowed	2	12.5
Total	16	100.0
<b>Number of Children</b>		
0	3	18.8
2	8	50.0
3	4	25.0
4	1	6.3
Total	16	100.0
<b>Religion</b>		
Neither religious or spiritual	1	6.3
Spiritual but not religious	4	25.0
Religious	11	68.8
Total	16	100.0
<b>Importance of Religion</b>		
Not important	4	25.0
Somewhat important	2	12.5



Very important	10	62.5
Total	16	100.0
<b>Education level</b>		
Less than 8 <sup>th</sup> grade	2	12.5
High School graduate	6	37.5
Some college	6	37.5
Post-college graduate work	2	12.5
Total	16	100.0
<b>Payer</b>		
No insurance	1	6.3
Medicaid	1	6.3
Private insurance	7	43.8
Total	16	100.0
<b>Illness</b>		
Cancer	10	62.5
Cardiac	2	12.5
Respiratory	2	12.5
Other	2	12.5
Total	16	100.0

#### *Description of Instrument Characteristics.*

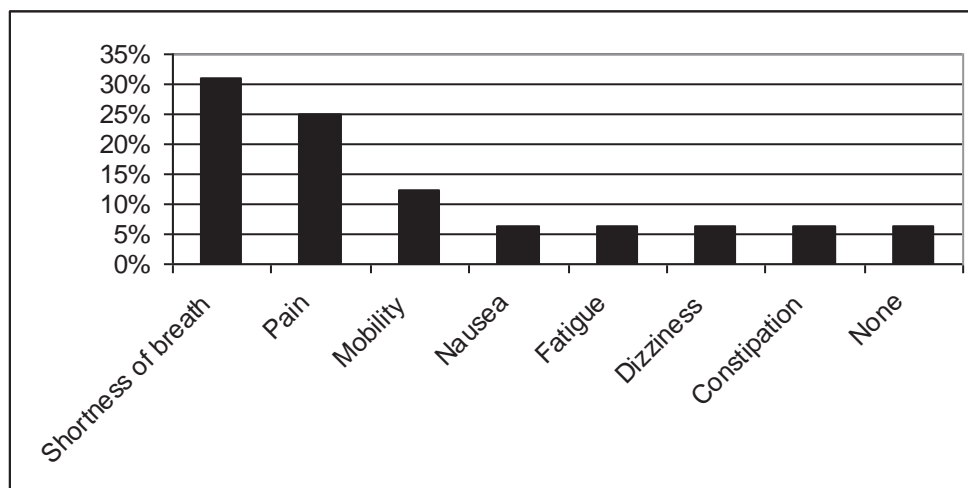
The results of p-values tests are not statistically significant and indicate weak evidence against the null hypothesis. Based on the p-value results the null hypothesis can not be rejected. The Null hypothesis states that there will be no difference in the patient's perception of their quality of life and their caregiver's perception of their quality of life as measured by The McGill Quality of Life Questionnaire.

Based on the Cronbach's alpha the internal consistency (reliability) for this study for the patient scores was 0.625 and for the families it was 0.606 which does not meet the standard of 0.70 or greater. The Cronbach's alpha if an item was deleted for the patient questions would 0.691 if question number eight was removed. Question eight asks "Over the past two (2) days when I thought of the future, I was: Not afraid 0 1 2 3 4 5 6 7 8 9 10 Terrified". For the families responses to the questions if question number four was removed the Cronbach's alpha would be 0.709 Question four asks "Over the past two (2) days I have felt physically terrible 0 1 2 3 4 5 6

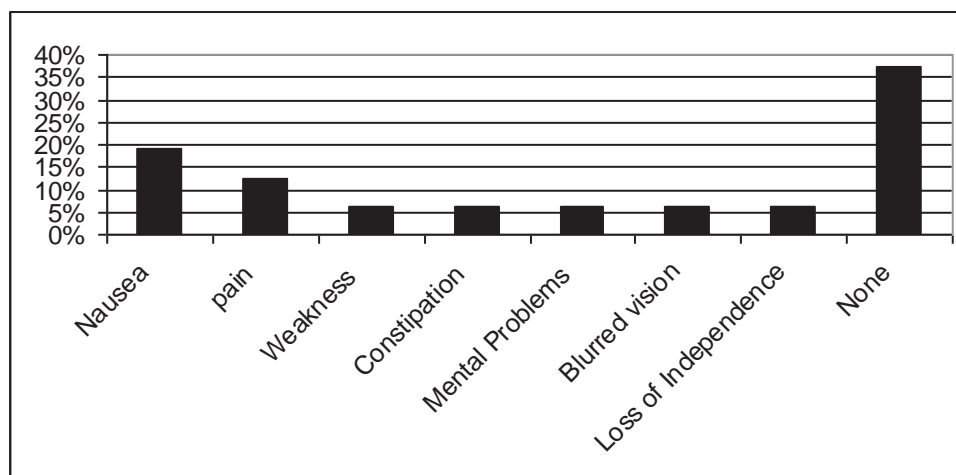
7 8 9 10 physically well”. If question number eight was removed the Cronbach’s alpha would be 0.706. By removing question number eight for both the patient and the family data the Cronbach’s alpha would meet the acceptable level of 0.70 for internal consistency (reliability).

#### *Troublesome symptoms.*

When asked the following question “Over the past two (2) days, one troublesome symptom has been” the most common primary troublesome symptom was shortness-of-breath followed by pain. The second most common troublesome symptom was nausea followed by pain. Only one patient listed a third troublesome symptom and that was lack of sleep. This finding supports previous research done by Nelson that reports 55-75% of patients experience pain, discomfort, anxiety, sleep disturbances, and unsatisfied hunger while hospitalized (Nelson, 2001). This finding is important so that healthcare administrators and providers can continue to look for ways to better manage patient’s symptoms leading to improved quality of life.



*Figure 1: Frequency of Troublesome Symptoms Reported First*



*Figure 2: Frequency of Troublesome Symptoms Reported Second Scoring.*

Part “A” of the McGill Quality of Life Questionnaire is a single-item scale (MQOL-SIS) measuring overall quality of life. It is not used in the total MQOL but as a comparison to the MQOL scores. Prior to calculating the MQOL scores or data analysis the following questions were transposed: 1, 2, 3, 5, 6, 7, and 8 based on scoring guidelines for The McGill Quality of Life Questionnaire.

#### MQOL Sub Measures:

**Physical symptoms:** This sub measure asks the patient to list the most troublesome symptoms in the past two (2) days and then asks the patient to rate that symptom on a 1 to 10 scale with 1 being “no problem” and 10 being a “tremendous problem”.

**Physical well-being:** this question asks the patient “over the past two (2) days I have felt.... The scoring is from 1 to 10 with one being “physically terrible and 10 being “physically well”.

**Psychological:** this score is the mean scores from item 5, 6, 7, and 8 (all four transposed).

**Existential:** the score is the mean of the scores for items 9, 10, 11, 12, 13 and 14.

Support: the score is the mean score for items 15 and 16. Refer to appendix B for the full survey tool. The total MQOL score is the mean of the 5 sub-measure scores.

The results of the research are included in the following tables.

*Analysis of Relationships and Differences.*

The largest difference between the patient and caregiver response was for question number four, physical well-being. This question reads “Over the past two (2) days I have felt... The scale is from 1 to 10 with 1 being physically terrible and 10 being physically well. The patients mean score was 8.29 while the caregivers mean score was 7.43 with a difference of 0.86. The patients scored their physical well-being higher then did the caregivers. The other question that was significantly different was for the existential subscale. The patients mean score was 5.9889 while the mean score for the caregivers was 6.8333. The difference in the mean between the patient and the caregivers was 0.84 with the caregivers scoring this item higher than did patients.

*Descriptive Statistics for Subscale Scores.*

Subscale	Mean	N	Std. Deviation
Patient psychological subscale	5.1667	15	1.83144
Family psychological subscale	5.3929	7	1.36822
Patient Existential subscale	5.9889	15	2.68703
Family existential subscale	6.8333	7	2.43432
Patient support subscale	7.3000	15	1.60134
Family support	7.5714	7	2.55650

subscale			
Patient physical symptom subscale	3.2500	14	1.77320
Family physical symptom subscale	3.4571	7	1.20258
Patient McGill 4	8.29	7	1.976
Family physical well-being	7.43	7	2.637

#### *Correlation Analysis and Results.*

Pearson's correlation coefficient was used to analyze the data to test for the strength and direction of the relationship between the patient and the caregiver's responses to the questions. Based on the paired samples correlations there is a weak correlation noted in the five subscales with a negative correlation noted in the psychological, physical symptom and physical well-being. The results indicate that there is a weak correlation but is limited due to the small sample size in this project.

Subscale	Correlation
Patient/Family psychological subscale	-.260
Patient/Family existential subscale	.132
Patient/Family support subscale	.357
Patient/Family physical symptom subscale	-.242
Patient/Family physical well-being	-.379

*Paired Sample t-test.*

T-distributions were used in this study to analyze the results due to the small sample size. The t-test analyzed the differences in the means of the two samples measured; the patient and the caregiver responses. The largest t-test score was for the patient/family psychological subscale. The biggest difference in the mean scores was for this item with a t-value of -0.749. The second largest t-test value was for patient/family physical well-being with a score of 0.589. Confidence intervals were also used to determine that the interval contained the population mean. A small confidence interval reflects greater precision while a large interval will generate greater confidence. The largest interval in this study was for patient/family physical well-being with the effect size being as great as a negative 2.702 or as great as 4.416. Because the range of the interval in this data contains both negative and positive values it is not very precise.

**Paired Sample t-test: Means Between Patient and Family Perceptions of Subscales**

Subscale	Mean	95% Confidence Interval of the Difference: Lower	95% Confidence Interval of the Difference: Upper	t statistics	Sig. (2-tailed) p- values
Patient/Family psychological subscale	-.60714	-2.59097	1.37669	-.749	.482
Patient/Family existential subscale	.47619	-2.13122	3.08360	.447	.671
Patient/Family support subscale	.42857	-1.96576	2.82290	.438	.677
Patient/Family physical Symptom subscale	-.45714	-3.03117	2.11689	-.435	.679
Patient/Family physical well-being	.857	-2.702	4.416	.589	.577

In summary, the results of this quantitative pilot study demonstrated that p-values were statistically significant and indicated weak evidence against the null hypothesis. Cronbach's

alpha (internal reliability) would be 0.691 for patients and 0.706 for caregivers if question number eight was removed. Pearson's correlation coefficient demonstrated a weak correlation between the patients and caregivers responses with a negative correlation for psychological, physical symptoms, and physical well-being subscales. The largest difference between patient/family was for the question on physical well-being. The mean score for patients was 8.29 while the family mean was 7.43. T-test results analyzed the difference in the mean of the two samples. The largest t-test score was the patient/family psychological subscale at -0.749.

## Chapter 5: Discussion

Based on the results of this pilot study there is a weak correlation between the patient and families responses to the patient's quality of life as measured by the McGill Quality of Life Questionnaire. Type II errors can not be ruled out in this study due to the small sample size. Based on the large p-value results in this study there is weak evidence against the null hypothesis. You can not reject the null hypothesis based on this pilot study. Based on the results of this study further investigation is warranted to determine if a larger sample size would lead to a statistically significant result and illumination of the findings. "Published studies have generally found moderate to high levels of agreement concerning health-related quality of life (HRQOL), with less agreement for psychological domains than for physical domains and less agreement between patients and health care providers than between patients and caregivers" (Kutner, 2006 p 301).

This study had several limitations including the small sample size, responses to the questionnaires were done at a single point in time, factors such as respondent's mood, energy level, degree of interest in answering could not be controlled.

### *Recommendations for further study.*

Instruments should be used to test whether or not interventions by healthcare professionals do improve the burdens, needs, and quality of life of patients and caregivers. Future research should also focus on the differences between the patient perception of their quality of life and the caregiver's perception of the patient's quality of life. "The usual conditions for effective coping and the attainment of a degree of peace at the end of life include good communication and trust among patient, family, and clinical team, the ability to share fears and concerns, as well as



meticulous attention to physical comfort and psychological and spiritual concerns” (Block, 2006 p 752).

Research supports that “rapid increases in the number of new hospital programs, as well as early studies indicating improved clinical, satisfaction, and utilization outcomes suggest that palliative care services are likely to become a routine and well-integrated part of the healthcare continuum in the United States over the next several years” (Meier, 2006, p 25). Healthcare administrators are interested in programs that provide high-quality, cost effective healthcare to the communities they serve. This study will add to the body of knowledge related to palliative care patients and their caregivers and the indicators that are important to their quality of life. This will allow for interventions that focus time, energy, and resources to improve these indicators.

## Reference List:

- Ainslie, N. (1997). Letter to the editor. *Annals of Internal Medicine*, 127(3), 242.
- Bertolino, M., & Heller, K. S. (2001). Promoting quality of life near the end of life in Argentina. *Journal of Palliative Medicine*, 4, 423-430.
- Block, S. D. (2006). "Psychological Issues in End-of-Life Care." *Journal of Palliative Medicine* 0(3): 751-772.
- Bridge, M., D. I. Roughton, et al. (2002). "Using caregivers-as-proxies to retrospectively assess and measure quality of dying of palliative care clients." *American Journal of Hospice and Palliative Care* 19(3): 193-199.
- Byock, I. (2006). "Improving palliative care in intensive care units: Identifying strategies and interventions that work." *Critical Care Medicine* 34(11): S302-S305.
- Campbell, M. L. (2006). "Palliative care consultation in the intensive care unit." *Critical Care Medicine* 34(11): S355-S358.
- Cohen, S. R., P. Boston, et al. (2001). "Changes in quality of life following admission to palliative care units." *Palliative Medicine* 15: 363-371.
- Connors, A. F., Dawson, N. V., & Desbiens, N. A. (1995). A controlled trial to improve care for seriously ill hospitalized patients. *JAMA*, 274, 1591-1598.
- Deeken, J. F. and K. L. Taylor (2003). "Care for the caregivers; a review of self-reported instruments developed to measure the burdens, needs, and quality of life of informal caregivers." *Journal of Pain and Symptom Management* 26(4): 922-953.
- Fainsinger, R. L. and A. L. Romer (2001). "Addressing quality of life at the Edmonton palliative care program." *Journal of Palliative Medicine* 4(3): 417-422.

- Ferrell, B., Grant, M., Padilla, G., Vemuri, S., & Rhiner, M. (1991). Their experience of pain and perceptions of quality of life: validation of a conceptual model. *The Hospice Journal*, 7, 9-24.
- Ferrans, C. E., & Powers, M. J. (1985). Quality of life index: development and psychometric properties. *ANS*, 8, 15-24.
- Fine, R. L. (2004). "The imperative for hospital-based palliative care: patient, institutional, and societal benefits." *BUMC Proceedings* 17: 259-264.
- Greipp, M. E. (1996). "SUPPORT study results - implications for hospice care." *The American Journal of Hospice and Palliative Care* May/June: 38-45.
- Huitt, W. Educational Psychology Interactive. Retrieved January 17, 2008, from <http://chiron.valdosta.edu>
- Jochman, H. R. (2006). "Quality of life in palliative care cancer patients: a literature review." *Cancer and Palliative Care* 10: 1188-1195.
- Johnson, J. O., D. P. Sulmasy, et al. (2007). "Patients' experience of being a burden on family in terminal illness." *Journal Of Hospice and Palliative Nursing* 9(5): 264-269.
- Kaasa, S. and J. H. Loge (2003). "Quality of life in palliative care; principles and practice." *Palliative Medicine* 17: 11-20.
- Kassa, S. (2001). "Assessment of quality of life in palliative care." *Journal of Palliative Medicine* 4(3): 413-416.
- Kutner, J. S., L. L. Bryant, et al. (2006). "Symptom distress and quality-of-life assessment at the end of life: the role of proxy response." *Journal of Pain and Symptom Management* 32(4): 300-310.

- Kutner, J. S., L. L. Bryant, et al. (2007). "Time course and characteristics of symptom distress and quality of life at the end of life." *Journal of Pain and Symptom Management* 34(3): 227-236.
- Kutner, J. S. and D. E. Nowels (2003). "Confirmation of the 'disability paradox' among hospice patients: preservation of quality of life despite physical ailments and psychosocial concerns." *Palliative and Supportive Care* 1: 231-237.
- Maher, D. and L. Hemming "understanding patient and family: holistic assessment in palliative care." *British Journal of Community Nursing* 10(7): 318-322. .
- Meier, D. E. (2006). "Palliative care in hospitals." *Society of Hospital Medicine*.
- Morrison, R. S. (2005). "Health Care system factors affecting end-of-life care." *Journal of Palliative Medicine* 8(1): S-79-S-87.
- Morrison, R. S., C. Maroney-Galin, et al. (2005). "The growth of palliative care programs in United States hospitals." *Journal of Palliative Medicine* 8(6): 1127-1134.
- Nelson, J. E. and M. Danis (2001). "End-of-life care in the intensive care unit: Where are we now?" *Critical Care Medicine* 29(2): N2-N9.
- Salisbury, C., N. Bosanquet, et al. (1999). "The impact of different models of specialist palliative care on patients' quality of life: a systematic literature review." *Palliative Medicine* 13: 3-17.
- Tierney, R. M., S. M. Horton, et al. (1998). "Relationships between symptom relief, quality of life, and satisfaction with hospice care." *Palliative Medicine* 12: 333-344.
- Tilden, V. P., S. Tolle, et al. (2002). "Measurement of quality of care and quality of life at the end of life." *The Gerontologist* 42 (Special issue III): 71-80.

World Health Organization. Retrieved January 16, 2008, from <http://www.who.int>

Retrieved January 16, 2008, from [www.macmillan.org](http://www.macmillan.org)

**Appendix A: Patient Demographics**  
**Information about You**

1. Your age\_\_\_\_\_years
2. Your sex
  - a. male
  - b. female
3. Your ethnicity background
  - a. White
  - b. Black
  - c. Hispanic
  - d. Asian
  - e. Native American
  - f. Pacific Islander
  - g. Other\_\_\_\_\_
4. Your living situation
  - a. single
  - b. married
  - c. domestic partner
  - d. separated
  - e. divorced
  - f. widowed
5. Number of children (non-dependent or dependent)\_\_\_\_\_
6. What is your religious belief/spirituality
  - a. Neither spiritual nor religious
  - b. Spiritual but not religious
  - c. Religious (please specify\_\_\_\_\_)
7. How important is religion or faith to you?
  - a. Not important
  - b. Somewhat important
  - c. Very important
8. Education level completed
  - a. Less than 8<sup>th</sup> grade
  - b. High school graduate
  - c. Some college
  - d. College graduate
  - e. Post-college graduate work
9. I have
  - a. No insurance
  - b. Medicaid
  - c. Medicare
  - d. Private insurance

What is your illness?\_\_\_\_\_

## Appendix B:

# McGILL QUALITY OF LIFE QUESTIONNAIRE

## STUDY IDENTIFICATION #: DATE:

### Instructions

The questions in this questionnaire begin with a statement followed by two opposite answers.

Numbers extend from one extreme answer to its opposite.

Please circle the number between 0 and 10 which is most true for you.

There are no right or wrong answers.

Completely honest answers will be most helpful.

### EXAMPLE:

I am hungry:

**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely**

- If you are not even a little bit hungry, you would circle 0.
- If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.
- If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.
- If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.
- If you are extremely hungry, you would circle 10.

### BEGIN HERE:

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW YOU HAVE  
BEEN FEELING JUST IN THE PAST TWO (2) DAYS.

### PART A

Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past two (2) days the quality of my life has been:

**very bad** 0 1 2 3 4 5 6 7 8 9 10 **excellent**

Please continue on the next page...

### PART B: Physical Symptoms or Physical Problems

(1) For the questions in Part "B", please list the **PHYSICAL SYMPTOMS OR PROBLEMS** which have been the biggest problem for you over the past **two (2)** days. (Some examples are: pain, tiredness, weakness, nausea, vomiting, constipation, diarrhea, trouble sleeping, shortness of breath, lack of appetite, sweating, immobility. Feel free to refer to others if necessary).

(2) Circle the number which best shows how big a problem each one has been for you

#### OVER THE PAST TWO (2) DAYS.

(3) If, over the past two (2) days, you had **NO** physical symptoms or problems, or only one or two, answer for each of the ones you have had and write "none" for the extra questions in Part B, then continue with Part C.

1. Over the past two (2) days,  
one troublesome symptom has been:\_\_\_\_\_.

(write symptom)

**no problem** 0 1 2 3 4 5 6 7 8 9 10 **tremendous**  
**problem**

2. Over the past two (2) days,  
another troublesome symptom has been:\_\_\_\_\_.

(write symptom)

**no problem** 0 1 2 3 4 5 6 7 8 9 10 **tremendous**  
**problem**

3. Over the past two (2) days,  
a third troublesome symptom has been:\_\_\_\_\_.

(write symptom)

**no problem** 0 1 2 3 4 5 6 7 8 9 10 **tremendous**  
**problem**

Please continue on the next page...



4. Over the past two (2) days I have felt:  
**physically** 0 1 2 3 4 5 6 7 8 9 10 **physically**  
**terrible well**

**PART C** Please choose the number which best describes your feelings and thoughts **OVER THE PAST TWO (2) DAYS.**

5. Over the past two (2) days, I have been depressed:  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely**

6. Over the past two (2) days, I have been nervous or worried:  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely**

7. Over the past two (2) days, how much of the time did you feel sad?  
**never** 0 1 2 3 4 5 6 7 8 9 10 **always**

8. Over the past two (2) days, when I thought of the future, I was:  
**not afraid** 0 1 2 3 4 5 6 7 8 9 10 **terrified**

9. Over the past two (2) days, my life has been:  
**utterly** 0 1 2 3 4 5 6 7 8 9 10 **very**

**meaningless purposeful**  
**and without and**  
**purpose meaningful**

10. Over the past two (2) days, when I thought about my whole life, I felt that in achieving life goals I have:

**made no** 0 1 2 3 4 5 6 7 8 9 10 **progressed to**  
**progress complete**  
**whatsoever fulfillment**

Please continue on the next page...

11. Over the past two (2) days, when I thought about my life, I felt that my life to this point has been:  
**completely** 0 1 2 3 4 5 6 7 8 9 10 **very**

**worthless worthwhile**

12. Over the past two (2) days, I have felt that I have:

**no control** 0 1 2 3 4 5 6 7 8 9 10 **complete**

**over my control over**

**life my life**

13. Over the past two (2) days, I felt good about myself as a person.

**completely** 0 1 2 3 4 5 6 7 8 9 10 **completely**

**disagree agree**

14. To me, the past two (2) days were:

**a burden** 0 1 2 3 4 5 6 7 8 9 10 **a gift**

15. Over the past two (2) days, the world has been:

**an** 0 1 2 3 4 5 6 7 8 9 10 **caring and**

**impersonal responsive to**

**unfeeling place my needs**

16. Over the past two (2) days, I have felt supported:

**not at all** 0 1 2 3 4 5 6 7 8 9 10 **completely**

© 1995 Robin Cohen

11. Over the past two (2) days, when I thought about my life, I felt that my life to this point has been:  
**completely** 0 1 2 3 4 5 6 7 8 9 10 **very**

**worthless worthwhile**

12. Over the past two (2) days, I have felt that I have:

**no control** 0 1 2 3 4 5 6 7 8 9 10 **complete**

**over my control over**

**life my life**

13. Over the past two (2) days, I felt good about myself as a person.

**completely** 0 1 2 3 4 5 6 7 8 9 10 **completely**

**disagree agree**

14. To me, the past two (2) days were:

**a burden** 0 1 2 3 4 5 6 7 8 9 10 **a gift**

15. Over the past two (2) days, the world has been:

**an** 0 1 2 3 4 5 6 7 8 9 10 **caring and**

**impersonal responsive to**

**unfeeling place my needs**

16. Over the past two (2) days, I have felt supported:

**not at all** 0 1 2 3 4 5 6 7 8 9 10 **completely**

© 1995 Robin Cohen